

## **Appendix 7**

### **Availability of Services For Treatment**

The task force found that there is a need for improved early detection and access to early intervention, access to life long, multi-disciplinary services, and professional training to build capacity for services in the community. Autism can be detected by 18 months. However, the average age of diagnosis is much later. According to a 1999 study conducted in Philadelphia County, using Medicaid data, Caucasian children were diagnosed at age 6 years, 3 months; African American children were diagnosed at age 7 years, 9 months; and Latino children were diagnosed at 7 years, 4 months. It was also noted in the study that African American children were diagnosed 1.5 years later than Caucasian children, and required three times the number of visits to get a diagnosis. Benefits of early intervention should be made available to all children with ASD from a young age.

#### **Early screening and medical providers**

The key to early identification of children with ASD is working closely with the medical community. Most children obtain health care on an ongoing basis from birth, giving physicians an opportunity to develop on-going, trusting, confidential relationships with families. Many parents consider their physician to be a trusted advisor on the health and development of their child, an ideal position for identifying and referring children with developmental delays. It is essential for physicians to be able to identify young children at risk for ASD, refer the children for appropriate assessment, and assist the family with information and resources.

Medical providers need more training and incentives for using an early screening tool. Screening tools are available to assist in identifying children with ASD as early as 18 months. These tools include the Checklist for Autism in Toddlers (M-CHAT); First Signs; and Autism Alert. Without early screening, children do not receive the substantial interventions they need, and the results are that many remain mute their entire lives, 75 percent are mentally retarded and need lifelong intensive care, 41 percent require psychiatric hospitalization, and very few develop meaningful friendships or marry.

#### **Access to early intervention**

National Research Council recommendations for early intervention stress that services should begin as soon as ASD is suspected, include a minimum of 25 hours per week, 12 months per year, and be a systematically planned, developmentally appropriate educational activity towards identified objectives. Priorities should include functional spontaneous communication, social instruction delivered throughout the day in various settings, cognitive development and play skills, proactive approaches to behavior problems, and the setting should include typically developing children.

Common elements of effective early intervention programs include (1) comprehensive curriculum, addressing core domains of imitation, language, toy play, and social interaction; (2) sensitivity to normal developmental sequences, (3) highly supportive teaching strategies based on applied behavioral analytic procedures, (4) behavioral strategies for reducing interfering behaviors, (5) involvement of parents as partners, (6) gradual/careful transition from highly supportive environment (usually 1 on 1) to less structured environment (small group), (7) highly trained staff, (8) supervisory and review mechanisms, (9) intensive, i.e., at least 25 hours per week of structured intervention for at least two years (per National Research Council recommendations), and (10) onset of intervention by 2 years.

## **Access to life-long, multi-disciplinary services in a comprehensive health care model**

Transitions (for example, from early intervention programs to elementary school or high school to adult programs) are especially vulnerable periods. A proactive approach prevents serious problems, avoids costly care (e.g., full time aide, psychiatric hospitalization) and offers hope for a productive, satisfying life for all individuals. Ongoing services needed by children in grade school through adolescence include school services that are sensitive to the needs of children with ASD; physician related services such as pharmacological treatment for anxiety and medical conditions such as seizures; social/vocational training; and periodic assessment and counseling to provide appropriate tools for handling new behavioral challenges and emotional issues.

Treatment across all ages should be individualized and multi-disciplinary, and should include: Medical needs (metabolic/genetic conditions (10-20% of population), seizures (25% of population), sleep disorders, gastrointestinal problems, allergies, co-morbid psychiatric conditions; psychosocial needs, educational needs, speech and language services, and occupational therapy. Multi-disciplinary care includes psychologists, educators, applied behavior analysts, speech/language pathologists, occupational therapists, and medical professionals.